

Barriers to improving access to therapy treatment for tics in the UK

By Dr. Tara Murphy & Seonaid Anderson

The European clinical guidelines for Tourette Syndrome suggest that behavioural therapies (BT) are 'first line treatments for tics for both children and adults'. However, according to Dr. Tara Murphy and Dr. Seonaid Anderson and colleagues, a barrier to delivering this in the UK is a lack of access to specialised psychologists and therapists. To relieve this problem there has been successful work on BT delivered by telemedicine, group interventions and there are current projects using remote access and online treatments. Tourettes Action (TA) is a national charity in the UK that offers subsidised training in BT with the hope of increasing the access of patients to BT. The researchers examined the number of people attending the BT training and whether this translates into additions to the TA list of available therapists. TA has a list of therapists across the UK who have been trained and have expert knowledge and experience in delivering BT for tics both privately and via the NHS which is made available to patients on request.

195 clinicians were trained in the UK by TA from 2013-2017 in Glasgow, Liverpool and London. Many of the trainees said they would be happy to have their details added to the TA list after training however, this only translated to a quarter of them joining. On examination, some of the reasons for therapists not joining the TA list included having no patients with tics at that time, although they perhaps might in the future. Issues relating to NHS services, such as having no capacity to see additional patients and being unable to take on more referrals. A lack of positivity from employers or service managers often related to service commissioning or lack of awareness of TS. Some trainees were willing to consider private work (in conjunction with their NHS work) which would allow them to join the TA therapist list. Importantly, once trained the lack of access to supervision expertise & subsequent lack of confidence seems to be an issue. TA aims to provide support in their clinical consultation sessions provide support to therapists who lack this peer-support opportunity in their current work situations.

To conclude Dr. Murphy and Dr. Anderson would surmise that it is very difficult to measure the impact



TA training has had and whether it has increased the numbers of clinicians/therapists offering BT in the UK. What there does seem evidence of, is that there is extreme patchiness in the UK in terms of commissioning arrangements for Tourette Syndrome. Without NICE guidelines or clear clinical pathways (such as those for other neurological conditions such as epilepsy), the situation may well remain unclear with patients having to find therapists themselves and fight to get funding for behavioural therapy to manage their tics.

About the authors:

Dr. Tara Murphy

Dr. Tara Murphy is a Consultant Paediatric Neuropsychologist and Clinical Psychologist. She worked at Great Ormond Street Hospital between 2003 and 2017 in neuropsychology and intervention services. In 2012, Tara co-led the National specialist Tourette syndrome clinic and developed services and completed research. She has written two books (Chowdhury and Murphy, 2017; Murphy and Millar, 2019) and many papers on Tourette syndrome. Tara is currently living in Kampala, Uganda volunteering at Butabika National Referral Hospital as part of the Butabika east London Link. She is treating and teaching other professionals how to treat children with tics and many other disorders.

Seonaid Anderson

Seonaid is a Chartered Psychologist and a member of ACAMH and BPS. I have experience of clinical research with children and young people. I am currently research manager for Tourettes Action where I manage the research awards programme. A large part of my job involves being an ambassador for Tourettes Action and to raise public awareness of Tourettes Syndrome and the role of research in improving the lives of people with Tourettes Syndrome and their families via Patient and Public Involvement (PPI) initiatives and providing professional support to clinicians.